HEIRS ANNUAL CLINICAL FOLLOW-UP FORM
For completion by Participants

Participant ID ☐☐-☐☐-☐☐☐☐☐-☐☐ Acrostic ☐☐☐☐☐☐

[affix ID label here]

Date of Form ☐☐/☐☐/☐☐ (Month/Day/Year) Completed by ☐☐☐

The HEIRS study is interested in knowing how you have been <u>since</u> your study exam on

☐☐/☐☐/☐☐ (Month/Day/Year) **. (date filled in by HEIRS staff)**

1. Have you had any of the following?

1a. Additional evaluation for iron overload (outside HEIRS)	1 ☐ Yes	2 ☐ No
1b. Phlebotomy (blood removal) as treatment	1 ☐ Yes	2 ☐ No
1c. Liver biopsy	1 ☐ Yes	2 ☐ No

If you have had any of the symptoms or conditions below, please tell us how they have changed since your HEIRS Study Exam. Please check the correct answer.

Instructions for questions 2 though 15:

- **Improved**: If you had a symptom or condition at the time of your study visit but do <u>not</u> have it now, your answer would be "Improved".
- **Worsened**: If you did <u>not</u> have a symptom or condition at the time of your study visit and you have it now, your answer would be "Worsened".
- **N/A**: If you did <u>not</u> have a symptom or condition at the time of your study visit and you do <u>not</u> have the symptom or condition now, your answer would be "N/A" (not applicable).
- If you had a symptom or condition at the time of the study visit, and you have the symptom or condition now, your answer would be either "**Improved**" *or* "**No Change**" *or* "**Worsened**".

2. Swelling of feet or ankles	1 ☐ Improved	2 ☐ No Change	3 ☐ Worsened	4 ☐ N/A
3. Change in skin color	1 ☐ Improved	2 ☐ No Change	3 ☐ Worsened	4 ☐ N/A
4. Unexplained weight loss	1 ☐ Improved	2 ☐ No Change	3 ☐ Worsened	4 ☐ N/A
5. Abdominal swelling or fluid	1 ☐ Improved	2 ☐ No Change	3 ☐ Worsened	4 ☐ N/A
6. Chronic fatigue/weakness	1 ☐ Improved	2 ☐ No Change	3 ☐ Worsened	4 ☐ N/A
7. Shortness of breath	1 ☐ Improved	2 ☐ No Change	3 ☐ Worsened	4 ☐ N/A
8. Joint stiffness/pain/ache	1 ☐ Improved	2 ☐ No Change	3 ☐ Worsened	4 ☐ N/A
9. Excessive thirst	1 ☐ Improved	2 ☐ No Change	3 ☐ Worsened	4 ☐ N/A
10. Polyuria (excessive urination)	1 ☐ Improved	2 ☐ No Change	3 ☐ Worsened	4 ☐ N/A
11. Unexplained abdominal pain or discomfort	1 ☐ Improved	2 ☐ No Change	3 ☐ Worsened	4 ☐ N/A
12. Unexplained confusion or memory loss	1 ☐ Improved	2 ☐ No Change	3 ☐ Worsened	4 ☐ N/A

13. **Unusual bleeding (vomiting or coughing up blood, blood in stool, or blood in urine)** 1 ☐ Improved 2 ☐ No Change 3 ☐ Worsened 4 ☐ N/A

14. **Abnormal heart rhythm, heart beat or action/arrhythmia.** 1 ☐ Improved 2 ☐ No Change 3 ☐ Worsened 4 ☐ N/A

15. ***For men only: Women go to # 16***
Trouble having an erection or loss of sexual drive 1 ☐ Improved 2 ☐ No Change 3 ☐ Worsened 4 ☐ N/A

16. **Have you experienced any other major changes in your health? 1 ☐ Yes 2 ☐ No**

If yes, please describe: _____

_____

17. **Have you changed primary care physicians, or are you seeing another doctor for treatment for iron overload? 1☐ Yes 2☐ No**

Name _____

Address _____

Phone _____

Do you give the HEIRS study permission to contact this physician to obtain information about your health care as it relates to iron overload? 1 ☐ Yes 2 ☐ No